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Towards a New Deal For Care and Carers

Report of the PSA Commission on Care, 2016





The
University
Of
Sheffield.



Political Studies
Association



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Foreword

Towards a New Deal for Care and Carers addresses one of the most urgent issues facing England today. The social care of older people has reached a tipping point – squeezed between huge demographic shifts and decades of underfunding, exacerbated by recent austerity policies.

There is a great deal of evidence accumulated – academic research, government reports, policy and campaign work – that has shown the extent of the problem and points to ways of addressing it. Often this evidence speaks to specific aspects of the issue – the impact on the NHS, care needs, personalisation agenda, funding issues or conditions of work for carers.

Towards a New Deal for Care and Carers builds on many of these perspectives in a new formulation that focuses on 3 Rs – recognition, redistribution and representation. This allows the report to show how the issue of caring for older people cannot be separated out from the redistribution of resources in order to fund social care properly and recognition of the value of care work (paid and unpaid) so as to improve the conditions of work of carers. To achieve this we need clear routes of consultation to ensure that those affected by policies – both those who receive and those who give care – are involved in making important decisions about their own care and caring.

This report, commissioned by the Political Studies Association, UK, poses a clear challenge to the government to provide substantially improved resources to address the crisis of social care. As the report concludes, this is not simply 'for economic reasons but to secure a fair and caring society where everyone gets the support they need, irrespective of their colour, class or creed'.

I welcome the publication of Towards a New Deal for Care and Carers and its contribution to the important work of making visible the urgency and necessity of investing in social care for older people in England.

Baroness (Ruth) Lister of Burtersett, House of Lords

Background to the Commission

This Commission was set up by the Political Studies Association, UK in September 2015. The aim of the Commission was to 'address an issue of strategic importance and reflect on how the study of politics might respond to challenges and opportunities raised by the changing scope and form of politics in the 21st Century.' Care of older people in England is the challenge this Commission addresses.

The crisis of care is a pressing issue of social policy. But there is an urgent need to ask broader questions about the politics, political economy and governance of care – especially within the context of the rapid fall in social spending that has accompanied the austerity-related cut backs in place since 2010. The Commission kept in its view the important question: Why, despite considerable and robust evidence already available, is care of older people not a priority for the government and society at large?

The composition of the Commission reflects both academic and campaigning organisations – Universities of Warwick and Sheffield, and the Fawcett Society and Women's Budget Group. The work of the commission is based on analysis of secondary research data and reports as well as primary research carried out by the Commission team.

The Commissioners

Co-Chairs



Belinda Phipps: After a period in the pharmaceutical sector then as a CEO for 26 years in the Health Service, Charity sector and a publishing company, Belinda has spent most of her career working for or alongside the NHS. Following twelve years' experience as a local councillor, a trustee and non-executive director she is now Chair of the Fawcett Society, CEO for the Science Council, Chair of the NMC Appointments Committee and Patron of PiP.



Sam Smethers: Sam joined Fawcett in August 2015 as Chief Executive. Prior to that she was the Chief Executive of Grandparents Plus for over six years. Sam is no stranger to equalities and gender issues having worked for both the Equal Opportunities Commission and the Equalities and Human Rights Commission. She also served as a Fawcett trustee between 2007 and 2010, was a trustee of Gingerbread for seven years and has nine years' experience working in Parliament.

Commissioners



Juanita Elias: Juanita is an Associate Professor in International Political Economy at the University of Warwick. She undertakes research and teaching on topics relating to care, migration and gender equality in the contemporary global economy.



Ruth Pearson: Ruth Pearson is Emeritus Professor of International Development at the University of Leeds and Co Chair of the Women's Budget Group. Ruth has extensive experience in international research and policy work for a range of organisations including UNDP, Plan International, the Department for International Development, the EU, UNWomen, Oxfam and CIDA. Her current work is focused on women's employment in the international economy, feminist economic policy, and migration, ethnicity and organisation.

Commission Research Assistants and Editor



Shirin M Rai: Shirin is a Professor in the department of Politics and International Studies. She has written extensively on issues of gender, work and governance. She has consulted with the United Nations' Division for the Advancement of Women, UNDP and PLAN. She was Director of the Leverhulme Trust programme on Gendered Ceremony and Ritual in Parliament (2007–2011). Her current work has three strands: feminist international political economy, gender and political institutions and politics and performance. Her latest books include *New Frontiers in Feminist Political Economy* (with Georgina Waylen).



Daniela Tepe-Belfrage: Daniela is lecturer in sociology, social policy and criminology at the University of Liverpool. She was previously based at the Sheffield Political Economy Research Institute. Her current research is concerned with gender in social policy and specifically with questions of family intervention.



Sara Wallin: Sara gained her PhD from the Department of Politics, University of Sheffield in 2016. Her ESRC funded doctoral research project explored feminist strategies in neoliberal governance, and she has since then worked as a Research Associate at Goldsmiths, University of London. She is currently guest-editing the British Politics upcoming issue 'Uncovering the Hidden Costs of Recovery' together with Daniela Tepe-Belfrage.



Nick Taylor: Nick worked in the Commission between June and August 2016. During this time, Nick was also employed as a Research Fellow in the Institute of Advanced Study at the University of Warwick. In 2015, he completed his PhD in the department of Politics and International Studies (PAIS) at Warwick. He is currently a research fellow at Goldsmiths College, University of London.



Eva Neitzert (Editor): is Director of the Women's Budget Group. Eva has worked senior roles with a range of social justice organisations, including the New Economics Foundation and Fawcett Society. Her research expertise centres on women in the labour market.

Acknowledgements

We would like to thank all those who participated in and supported the work of the Commission. Many different organisations and individuals contributed to our work– speaking at our events in Coventry and London, providing written submissions, giving us their time and agreeing to be interviewed in person, and reviewing and commenting on our work. A full list of these individuals is provided in the Appendix.

We are grateful to two student research assistants, Keira Koroma and Alexa Enache who assisted us in the early stages of the Commission’s work, to Phil Tutty who developed the Commission’s web site and to Eva Neitzert who carefully and painstakingly edited the report making it a much better read; she also calmed our nerves at critical junctures. Thanks also to Sue Himmelweit for her extensive comments on the report conclusions and recommendations.

The Commission was funded by the PSA, the University of Warwick Economic and Social Research Council (ESRC) Impact Accelerator Account, the Department of Politics and International Studies at the University of Warwick and the Department of Politics at the University of Sheffield. We appreciate this funding without which this work would not have been possible.

1. Introduction



The Political Studies Association Research Commission on Care was established in response to the intensifying crisis that is playing out in the delivery of care for older people and the failure of successive governments to acknowledge, and take action, to address this crisis.

Both in the UK and internationally, there is growing demand for care. Over the past sixty years, globally, the number of children has doubled, the elderly population has increased six-fold but the carer population only three-fold (UN, 2011). Over 4 million above 65 years old people in England are in need of regular care. According to the King's Fund, in the UK, 'Over the past five years, local authority spending on the essential care and support needed by older and disabled people has fallen by 11 per cent in real terms and the number of people getting state-funded help has plummeted by at least 25 per cent' (Humphries et al., 2016:6). The 2011 UK census identified that 6.5 million people are carers – an increase of 11% since 2001 (Carers UK, 2015a). However it is increasingly the case that those who are doing the caring for many of the frail elderly are often other older people who have care needs themselves.

The escalating crisis of care attendant upon these demographic shifts has until recently been mainly discussed in terms of rising costs to the state – including the NHS and local authorities – rather than to those engaged in doing this work. But there is growing recognition of the costs of caring for society more generally. In the UK, these costs have increased as a result of austerity policies that have seen the state withdraw from many care functions. Women have been disproportionately affected because of their role as the main providers of unpaid and paid care and also as they are more likely to be users of care services.

During the period of the Commission's work the referendum result that heralds the exit of the UK from the EU has introduced further uncertainties and complexities on the care landscape and risks further eclipsing the crisis in care as a political issue. Worryingly, Theresa May's government has, for the first time in eight years, downgraded the position of the Minister for Care so that this role now falls within the remit of a parliamentary under-secretary. A shift that for many in the sector reflects the way in which adult social care for older people is not viewed as a key political issue (Ashcroft, 2016; Clay, 2016).

Increasing care needs: the facts

- An estimated 4 million older people in the UK (36% of people aged 65–74 and 47% of those aged 75+) have a limiting longstanding illness. This equates to 40% of all people aged 65+.
- The aging population and increased prevalence of long term conditions have a significant impact on health and social care and may require £5 billion additional expenditure by 2018.
- If nothing is done about age-related disease, there will be over 6.25 million older people with a long-term limiting illness or disability by 2030: nearly 9% of the total population.
- Almost two thirds (59%) of people aged 80 and over in the UK have a disability

Age UK, Later Life in the United Kingdom June 2016, p. 8

The Commission builds on the work of many who have been campaigning and researching this issue, and aims to put the care crisis on the political agenda. Our starting point has been the acknowledgment that there is a crisis of care in England. Over the past 12 months, the Commission has evaluated the following five crucial dimensions in the future provision of care to older people in England:

(a) The role of fiscal austerity policies on the provision of care:

The effects of an increasing older population and its needs for care are being amplified by the austerity driven decline in public services, including the specific and direct reduction in social care expenditures. While local authorities have sought to safeguard social care through efficiency measures, services for older people have been subjected to an overall 15% cut in financing and new measures, such as the social care precept, are inadequate to bridge the gap, particularly in poorer areas. This report asks what the effects are of this continued erosion of public services.

(b) The governance of care:

While funding is a crucial aspect of delivering care, so is its governance. The Commission examined how different aspects of governance work together and whether funding is affecting the governance of care and whether reform of governance

mechanisms allow for easier access to care. In particular, the Commission sought to understand how increases in the marketisation, privatisation and domestication of care provision is affecting care delivery and the ability of governmental and non-governmental bodies to regulate it.

(c) The privatisation and marketisation of care:

Over the past decade, the provision of care has shifted increasingly to private providers even when services are directly commissioned by public authorities. The Commission examined both a privatisation process, whereby publically financed care is outsourced to private providers, and a marketisation of care, whereby public commissioning as well as individual purchasing of care has been accompanied by the entry of a range of commercial providers into the market. The Commission asked two key questions in relation to these processes: What are the ethical issues stemming from this privatisation of care? What are the differential effects of these changes on the population along the lines of gender, class, race, ability and age?

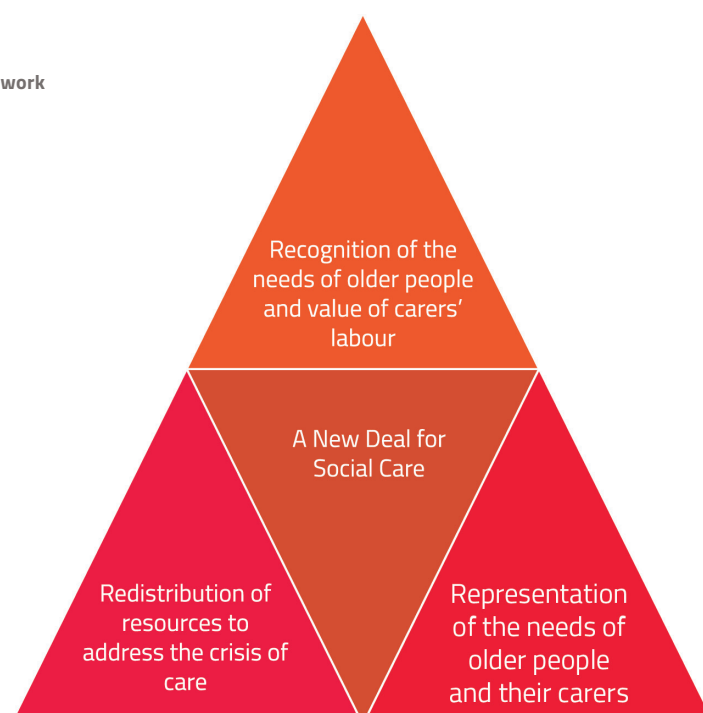
(d) The domestication of care: The increasing gap between publically financed provision of care and the growing need for care services at home, has seen a transfer of responsibility onto informal, unpaid care by family, friends and neighbours. This is trend that disproportionately impacts women and has implications for the ability of carers to combine paid and unpaid work. The Commission was particularly interested in how black, Asian and minority ethnic (BAME) citizens have been affected by service cuts, both as providers and recipients of care.

(e) The role of migration and precarious labour on the working conditions of carers: Just under a fifth of the adult social care workforce in England was born outside the UK and over a quarter of these workers were born in the EU, making the sector heavily reliant on migrant labour (Franklin & Brancati 2015: 11). The Commission sought evidence to assess how far and in what ways changing immigration patterns are affecting changes in paid care work. Key questions included: How is the deepening precariousness of paid care labour impacting the quality of care received? How do government priorities in relation to immigration targets impact who does the paid caring? How would a shortage of care workers affect care-users' ability to participate in the labour market?

The report argues that a New Deal for older people will require us to bring together three different aspect of care provision that are often not connected - the recognition of issues of care with the importance of redistribution of resources and representation of the voices of both those that are cared for and those that care (see Figure 1 and Fraser, 1995). A joined up analysis makes for better policy.

The next four chapters set out the shape of the care crisis and map out a New Deal for older people and those who care for them by examining the care landscape, how care is resourced, the challenges of accessing care services, and the issue of addressing the needs of those who provide care.

Figure 1: Analytical framework



Scope and Methodology

The Commission defined its parameters first, to focus on the care of older people rather than a wider enquiry into care which would have included child care and adult social care for those with disabilities; and second, to limit our focus to England rather than the UK as a whole. Further, the analysis was confined to the area of elder care provided by paid and unpaid workers in the public, private and domestic spheres. We therefore have excluded any discussion of the health care system or reforms to the NHS, in part because these issues command much higher attention among the public and policymakers.

Our work is based on a review of the primary and secondary literature as well as an online survey of 169 care workers, and interviews with care providers and local authority officials.

The Commission convened a call for written evidence between February and July of 2016 and received submissions from a number of local authorities and third sector organisations. In addition, the Commission held two evidence-gathering days. The first took place in Coventry and focussed on the work of paid and unpaid carers, with a particular focus on how the work of care impacts BAME communities. The second event, a policy-forum, was held in London and included presentations from key policy and campaign organisations, and care providers.

The recent referendum vote to exit from the EU has complicated the compilation of this report. Since neither the timing or the terms of Brexit have been finalised, this report can only flag what some of the potential issues may be for the care sector.

We hope that this report will be a useful intervention in the debates on social care for older people in England. Specifically, we hope that it will catalyse a more adequate and urgent response from government and key decision-makers than we have witnessed to date. The Commission's work confirms the deep crisis facing the care of older people. This crisis is now, not in the future. It demands a comprehensive response.

1. Detailed reports from these two events can be found on the Care Commission Website:

<http://www.commissiononcare.org/category/events>





2. The Care Landscape in England

There are significant demographic pressures facing the adult social care sector as well as those providing unpaid care going forward. The UK has an ageing population; census figures show that the number of residents in England and Wales aged 65 and over increased by nearly a million between 2001 and 2011, from 8.3 million to 9.2 million, a jump of 16% (ONS, 2013a). In 2015 the older population in the UK was estimated at 11.6 million people (17.8% of the population). Along with this growth in the older population, care needs have been increasingly unmet. Furthermore, the ONS predicts that the UK's population will continue to age, and without reform this will put further strain on services, budgets and carers.

Here we provide an overview of the care landscape in England today, highlighting the structure of the sector, the regulation of care, its financing, as well as access to, and the supply of, care. This review has uncovered several key, and often overlooked, issues:

1. That care needs to be understood as paid and unpaid work that is deeply gendered. Women are more likely to be involved in caring, whether paid or unpaid, and even when men are engaged in this kind of work various forms of gender inequality persist.
2. That the experience of being cared for is impacted not only by class and the ability of certain groups in society to afford to pay for their care, but also by factors relating to race and ethnicity.
3. That the care sector remains highly dependent on migrant labour and is thus impacted by ongoing changes to UK immigration regimes that have focussed disproportionately on low wage immigrant labour as a 'problem'.
4. That, while the care sector is increasingly privatized and marketized, the new regulatory environment appears unable to address some of the market failures and social injustices at work within the current care landscape.

Structure of Care of Older People in England

The provision of care for older people in England is a complex exercise, with many different actors involved in its provision and governance. Formal care of older people in England is organized into social care and health care, defined in section 9(1) and (2) of the Health and Social Care Act 2008 of the Health and Social Care Act.

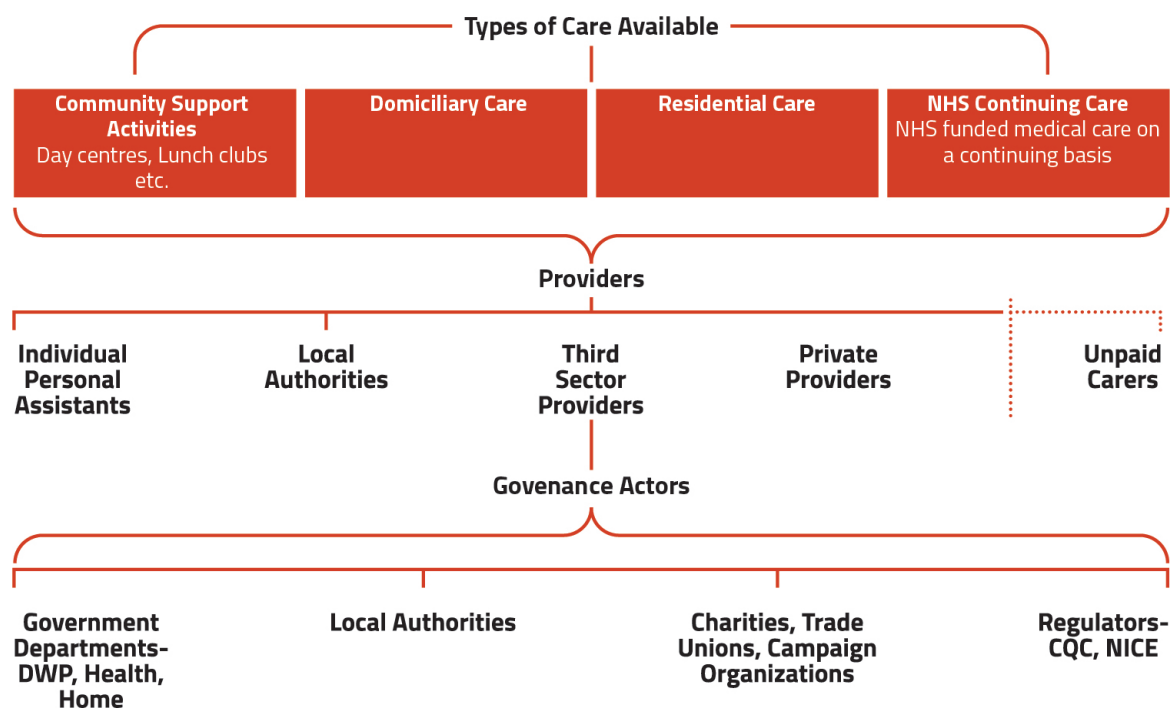
Health care includes all forms of health care provided for individuals, whether relating to physical or mental health, and also includes procedures that are similar to forms of medical or surgical care but are not provided in connection with a medical condition.

Social care includes all forms of personal care and other practical assistance provided for individuals who by reason of age, illness, disability, pregnancy, childbirth, dependence on alcohol or drugs, or any other similar circumstances, are in need of such care or other assistance.

In distinguishing between these two forms of care it is important to recognise that although health care is free at the point of use, state support for adult social care is means tested. But, as a recent report from ILC-UK makes clear 'many do not realise that they have to pay for care...' (Franklin, 2015: 4).

Social care – itself of different types – is provided and governed through formal and informal channels (see Figure 2 below).

Figure 2: The Organization of Care in England



Social care is divided into three broad categories – domiciliary care, residential care and NHS continuing care. There are multiple, private and public providers of social care, who are regulated by different formal and informal bodies. So, local authorities are responsible for formal care provision and payments are organized through means-testing. The provision, however, is often outsourced to ‘for profit’ or ‘not-for profit’ providers, who are in many cases large corporations dependent on private equity capital and therefore vulnerable to market shocks. The case of the collapse of the Southern Cross care chain in 2011 illustrated this vulnerability well.

The care workforce: paid and unpaid

There are approximately 1.45 million people working in the adult social care sector in England. More than half of these workers are employed in care homes and three-quarters as direct care workers (Skills for Care 2015: 20). A significant part of social care for older people is provided by family members and, to a lesser extent, in communities by neighbours and friends. The number of unpaid carers in England rose from 4.9 million in 2001 to 5.4 million in 2011 (Carers UK 2015a: 1-2). As Mortimer and Green point out, ‘The numbers caring informally for older people have fluctuated slightly in recent years, but in 2014 about one in six of the population were doing so, a third of them for more than 20

hours a week’ (2015:6). Taken together, this means that the unpaid work by carers is worth up to £119bn per year – more than the total spending on the NHS in England (Carers UK 2015a: 2).

Gendered Nature of Care and Caring

The provision and receipt of care, both paid and unpaid, is deeply gendered. More women than men provide paid and unpaid care for older people, and women are also more likely to be engaged in multiple forms of caring.

The adult social care workforce is 82% female. In direct-care provision, this proportion is even higher. By contrast, women account for only 46% of all economically active individuals in England (Skills for Care 2015: 36). This gender imbalance in the care sector is evident across different job categories – manager/supervisor, professional, direct care – although analysis of individual job roles shows that men are more represented at senior management levels (Skills for Care 2015: 36-7). In long-term care in England, recent analysis shows that jobs within the sector strongly reflect gendered norms, with 72% of technician jobs (e.g. maintaining and servicing equipment) performed by men but only between 4% and 12% of jobs in nursing roles (Hussein, Ismail & Manthorpe 2016: 40).

Unpaid care is less starkly imbalanced, but still falls more to women than to men. While men are increasingly involved in care, they tend to be involved more in the care of spouses than in the care of elderly parents. The 2011 census showed that 3.12 million of those providing unpaid care in England were women, or 58% of all unpaid carers. In the context of an ageing population, the age profile of carers means that people suffering from acute conditions such as dementia are often cared for by a spouse or relative who themselves have severe care needs. Unpaid family carers also face the stresses and strains of navigating what are often complex bureaucratic systems for accessing care (Mockford et al. 2016:7-9) – a burden of ‘co-ordination of care’ that may fall upon other family members who are less directly involved in day-to-day care activities.

Increasingly, people are juggling work and care, or multiple caring responsibilities such as for children as well as older and disabled relatives. This has been referred to as ‘sandwich caring’ or ‘dual caring’. Surveys show that the vast majority of sandwich carers are women and that women are four times more likely than men to give up paid work to do unpaid care work (Carers UK 2012: 12-23). The rising female employment rates, while seen as a success story for the UK, are also leading to an increasing ‘double burden’ for women who do paid work alongside their unpaid care responsibilities. This burden increases when jobs are insecure or poorly paid. Increased participation by older women in the labour market means this is true for grandmothers as well as mothers (Ben-Galim & Silim 2013).

In terms of the receipt of care, older women have higher needs than older men of the same age and are more likely to have unmet care needs (NAO 2014: 19). Women are more likely than men to suffer from dementia and long-term conditions such as osteoarthritis and rheumatoid arthritis (WBG 2015: 2). However, in some areas the gender gap for the receipt of care is narrowing. For example, in residential care in England and Wales the ratio of women to men fell from 3.3 to 2.8 between 2001 and 2011 (ONS 2014).

Evidence from the Commission

At our event ‘The Work of Care’ held in Coventry in March 2016, The Commission heard from organisations working with BAME groups.

These were some of the key points to emerge from the day:

- Speakers from the Alzheimer’s Society, Culture Dementia UK, the Chinese National Healthy Living Centre and participants representing the work of other organisations, were unanimous in their view that BAME groups should not be regarded by local authorities as ‘hard to reach’.
- Local community interlocutors such as religious organisations, community centres as well as smaller and more focused community health and social care organizations can play an important role in identifying individuals with care needs and supporting their carers.
- In some communities cultural and social stigma surrounds conditions such as dementia and efforts have been made to combat these.
- David Truswell of Culture Dementia UK cautioned against assuming that in BAME communities ‘folk look after their own’. He argued that there is often little cultural understanding of diseases such as dementia that have only recently become more prevalent with increasing life expectancy.
- Edie Chan from the Chinese National Healthy Living Centre discussed their attempts to dispel stigma through the development of a Chinese character for dementia – necessary because it served to ensure that the disease was not associated with ‘madness’.
- Participants also commented on the problem of the short-term nature of funding for projects specifically targeting BAME groups – for example one participant commented that in the case of care for people with dementia ‘people need stability and longevity, but all the funding is very short-term’.

See also Koroma (2016)

Ethnic Minorities, Care and Caring

The ethnic minority population of England is younger than the White British population, with the exception of White Irish, Indian and Black Caribbean groups (CPA 2013). However, the BAME older population is set to grow, and care provision will have to meet the specific challenges this brings. It is estimated that there are currently more than 800,000 BAME older people (aged 65 and over) in England and Wales, with this figure set to rise to 1.3 million by 2026 and 3.8 million by 2051 (Lievesley 2013: 1; see also Hussein 2016).

Previous studies have established that ethnicity has played a role in the uneven quality of the care services that older people receive, caused in part by issues of access to and information about services as well as stereotyped views concerning the needs of BAME older people (for example, the assumption that BAME communities 'look after their own') (Calanzani et al. 2013). The Care Quality Commission found a significant variation in access, experience and outcomes for different groups of people using care services. In particular, people in BAME groups are less likely to report that they have received information and support to access other services on discharge from hospital (CQC 2015: 1). This seems particularly problematic in the light that BAME groups are more likely to not have English as a first language (CQC 2015: 109). Furthermore, as a consequence of socio-economic and structural inequalities, BAME people are disproportionately affected by poor health and high rates of life-limiting illness, but are also less likely to have the savings or inherited wealth needed to cover care costs (Lipman 2014: 5).

Rather than a requirement for altogether separate services for BAME older people, the problem has been identified as a lack of recognition for their culturally specific needs within existing services (Manthorpe et al. 2009). Language barriers can put BAME older people, as well as BAME carers, at a significant disadvantage when it comes to accessing and using services (Gunaratnam 2007). Many older people require the support and advice of an advocate, often a family member, to negotiate the complexity of the care system. A national survey conducted in 2010–11 of social care users found that non-White groups report greater difficulties in getting the information they need (HSIC 2011: 56).

In many BAME communities, there are also problems associated with a lack of awareness or understanding of health conditions affecting older people. Dementia in particular is often misunderstood and highly stigmatised (Truswell 2013). In some Asian languages there is no term for dementia and in some BAME communities it is associated with mental illness and even considered contagious (APPG on Dementia 2013: 24–27; Nijjar 2012: 4).

With small government grants, projects at the local level have recorded examples of good practice in the provision of information and advice for BAME older people (e.g. Age Concern & Help the Aged 2010; see above text box detailing the discussion of this issue at our Coventry event). Worryingly, there is evidence to suggest that BAME voluntary social care organisations have experienced disproportionately greater funding cuts than mainstream voluntary service providers in the last few years, and that mainstream providers have reduced services specifically targeting BAME older people (Lipman 2015).

In addition to having specific care provision needs, we must also recognise that Britain's ethnic minorities play an important role in the delivery of care. It is estimated that 80% of the adult social care workforce has a white ethnic background and 20% a Black and minority ethnic (BAME) background. The adult social care workforce is therefore more ethnically diverse than the general population (15% BAME) and the economically active population (12% BAME) (Skills for Care 2015, 39). 87 per cent of managerial and supervisory jobs are done by white workers; BAME workers are in contrast 42 percent of registered nurses (Skills for Care, 2015:24.) From an equality perspective, it is concerning that BAME workers are more likely to be in lower paid roles in the care sector.

There is considerable regional variation in the ethnic composition of the care workforce. In the North East just 4% of the workforce has a BAME background. In the West Midlands and South East around a fifth of workers have a BAME background, whereas in London BAME workers are in a majority at nearly two-thirds of the workforce (Skills for Care 2015). Addressing low pay in the social care sector thus not only has implications in terms of the gender pay gap, but also is an essential step in ensuring racial equality, especially in cities such as London.

'They are good (neighbours) but I don't communicate with them because I don't speak English'.

'And then they sent an ambulance and she was trying to tell them to phone her son because she wanted him to be here but nobody was there to understand what she was saying'.

testimonies from older BAME people from Shaping Our Age, 2011, p. 41

Migration and Care

Migration is an important issue for the adult social care sector in England and it is imperative to consider the role of migrants in the workforce as the UK seeks to renegotiate its relationship with the EU and the rest of the world in the coming months and years. The care sector faces significant challenges in attracting and retaining staff, reflected in high vacancy and turnover rates, and migrant care workers have been essential in meeting the growing demand driven by an ageing population.

'She likes white people more than me. Sometimes, when she talks to me, she will know what I'm talking about, but if she sees other white people, she will say she can't hear what I'm talking about, 'I can't hear your accent, what are you saying.'

Zimbabwean female care assistant, UK live-in care worker cited in Walsh & Shutes (2013) p. 406

Migrants make up around a fifth of the adult social care workforce, with around 15% of workers estimated to have been born outside of the EU, and around 5% born in the EU outside the UK (Franklin & Brancati 2015: 25; Skills for Care 2015: 44). Between 2011 and 2014, the top five countries of origin of migrant care workers were Romania (13%), Poland (13%), India (12%), the Philippines (8%) and Nigeria (8%) (Skills for Care 2015: 45). The migrant care workforce is unevenly distributed across the country, with 46% of workers in London and 23% in the South East estimated to be of non-British nationality, but 10–12% in the South West, Yorkshire and Humber, the North West and the East Midlands (Skills for Care 2015: 41).

A number of changes to migration policy have recently seen a shift in the make-up of the migrant care workforce. If we consider the country of birth of care workers, then the proportion of non-UK born care workers in London rises to 61% (Skills for Care 2015: 44). In terms of the roles that migrant care workers are employed in, 150,000 work in care homes, 81,000 in domiciliary care and another 35,000 in other roles such as adult community care services (Franklin & Brancati 2015: 4).

In 2011 the Migration Advisory Committee (MAC) recommended that senior care workers be removed from the Tier 2 Shortage Occupation List and the Government introduced a cap on Tier 2 visas of 21,700 per year (APPG Migration 2011; Home Office 2010). In addition, as of April 2016, non-EU workers who enter the UK on a Tier 2 visa and who have spent more than five years working in the country are required to earn more than £35,000 per year or be faced with a possible order to leave (Home Office 2012). These policies have reversed a decades-long relationship between the share of EU and non-EU migrant arrivals in adult social care, so that by 2014 EU migrants accounted for 80% of new entrants to the workforce, in contrast to non-EU migrants at 20% (Franklin & Brancati 2015: 26). This has led, as Christensen and Guldvik (2013:16) point out to a somewhat 'paradoxical situation' whereby

those from outside the EU, who may have English language abilities due to historic colonial ties, are faced with strong restrictions while European migrants without the same language skills have unrestricted access.

Migrant workers – from both the EU and the Commonwealth have in general much higher and relevant qualifications for care work (Franklin and Brancati 2015: 38). However, as UK migration regulations frequently do not recognize the professional experience or qualifications of migrants, many are employed at occupational and pay levels well below UK workers with similar backgrounds (Green et al. 2014: 51). The probability of a UK-born worker holding a Level 4 qualification is estimated to be less than 10%, compared to 15% for migrant workers born outside the EU (Franklin & Brancati 2015: 38).

The increasingly restrictive migration policies already in place are making it difficult to meet the sector's needs. This is concerning as Britain's exit from the EU looks likely to usher in an even more restrictive regime. The reliance of the care sector on migrant workers is a product of underfunding, low pay and poor employment conditions (IOM 2010; Shutes & Chiatti 2012). This implies that without a change to these conditions further restrictive immigration policies will exacerbate recruitment and retention difficulties in the care sector and adversely affect the care of older people in England (Franklin & Brancati 2015).

The Care Act 2014

The Care Act 2014 is the latest and most wide-reaching regulatory change to social care law in the last sixty years. The Act introduced a national minimum threshold for social care rather than eligibility being set locally by councils. In April 2020 the remaining parts of the Care Act will come into effect, including how local authorities should charge for both residential care and community care, and the introduction of the 'care cap', relating to the maximum amount a person is asked to put up for their own care. Councils are now allowed to contract out functions such as assessment of care to private providers (including third sector not-for-profit providers).

The Commission's work found that whilst the principles of the Care Act are sound, its expectations are not. In a context of austerity and budget cuts, it is impossible to insist on a high level of care, assessment and regulation from the local authorities (see chapter 3). Further, the 2014 Care Act has introduced several new legal layers of local authority responsibility, yet in part this has meant formalising already existing policy rather than introducing new provision (LGA 2016).

3. Resourcing care



The care sector is facing a resourcing crisis. There has been a significant decline in local authority spending on adult social care as a result of austerity policies. At the same time, highly financialized private providers have become increasingly central to service delivery. These twin pressures are shaping the commissioning landscape for local authorities, impacting on decisions around closure and streamlining of services, the kinds of services that are commissioned, and investments in technological innovations.

Local authorities and senior figures within the sector are increasingly concerned that severe financial cuts to the sector are making it difficult for local authorities to meet their statutory duties towards carers and those with care needs. The resourcing gaps in the sector mean that care is increasingly being picked up by unpaid carers. We refer to this trend as the domestication of care and consider whether an assumption that unpaid carers will plug gaps means that care will remain a low priority for government intervention.

The Commission's research into the resourcing challenges facing the care industry identifies the following key issues:

1. The postponement of the Dilnot recommendation's for fairer care funding is indicative of the lack of political consensus around how the funding system should operate. It is now unlikely that recommendations made by Dilnot will ever be implemented, even in a modified form.
2. The deepening funding crisis impacts not only the recipients of care, but also places increased pressures on unpaid carers.
3. The severity of the local authority funding crisis means that it is difficult to see how further spending cuts, innovations and efficiencies could be achieved without shifting costs elsewhere in the system, such as acute care services.
4. Local authorities are struggling to fund programmes that support and identify unpaid carers. Unpaid carers are faced with a triple jeopardy: reduced formal services, reduced support for unpaid carers, and cuts to other local authorities services, such as lunch clubs and libraries, that provide information and respite.

Funding social care has been a long standing challenge, made worse by underfunding and intensifying as the demographics of England's population change. As we have noted above, addressing this challenge has not been a priority for the political elite. However, over a period, some interventions have been made to find answers for this growing problem of funding social care. The Commission on Funding of Care and Support led by Andrew Dilnot, which reported to government in July 2011, was a critical intervention in the debate on social care.

The Dilnot report

The main recommendation of the report was to cap individuals' lifetime contributions towards their social care costs somewhere between £25,000 and £50,000, after which they would be eligible for full state support. The most 'appropriate and fair figure' was considered to be £35,000. The cost to the state at this level was estimated to be around £1.7bn.

The report also recommended raising the means-tested asset threshold above which people must pay their full residential care costs from £23,250 to £100,000 and the creation of national standards for the assessment of care needs. Capping social care costs was intended to encourage a market in private insurance for people to cover the cost of their care up to the point of the threshold.

In 2013, the government decided to set the cap at £72,000 and increase the means-tested asset threshold to £118,000. The government committed to introducing the cap under the Care Act by April 2016, but this objective has now been deferred until 2020. The recommendations of the Dilnot report had been broadly welcomed across the sector and by the major political parties (Kings Fund 2011; Care and Support Alliance 2011) and its subsequent sidelining has led to disappointment among campaign groups (Hunter 2015; Humphries 2015).

Although broadly welcomed, some criticised the Dilnot report for not going far enough. The report did not set out how its recommendations were to be funded and there were questions about whether an insurance market would automatically emerge to cover the cost of care up to the threshold (Kelly 2011). The Trade Union Congress (TUC) supported the report but also called for

more ambitious proposals (Exell 2011), including the adoption of the Labour Government's White Paper on 'Building the National Care Service'. Published in 2010, this proposed a comprehensive high-quality care service for all adults, free at the point of delivery, and available to all adults regardless of where they lived, who they were, and the reason for needing care (HM Government 2010).

The lack of a plan or clear political consensus as to how the state's contribution to adult social care would be funded contributed to a lack of progress on the Dilnot recommendations. Dilnot had suggested that pensioners could start paying national insurance to meet the £2bn a year costs to the state – the first policy to earn the title of 'granny tax' (Mirror 2011). Paul Burstow MP, Minister of State for Care Services from 2010–2012, recommended in 2013 that the lifetime cap on self-funding be raised to £60,000, with government costs paid for by cuts to Winter Fuel Payments for wealthier pensioners and a capital gains tax at death (Burstow 2013). Labour MP Andy Burnham repeatedly proposed an estates tax of 10–15%.

After the Coalition Government decided to raise the lifetime cap on self-funding to £72,000 (and subsequently £75,000) criticisms increased from Labour. In May 2013, Shadow Health Secretary Andy Burnham claimed in the Commons that the cap was a 'mirage' because of the extra charges that were being asked of older people – such as for food and accommodation – and because of the cuts to council support (Hansard 13 May 2013, c359). Over 2013–14, Labour considered and ultimately rejected proposals for an estates tax of up to 15%. The policy was dropped in advance of the 2015 general election after it was branded a 'death tax' (Swinford 2015).

Funding Care and Austerity

Finding a sustainable and fair solution to the funding of adult social care has been compounded by years of austerity, particularly at the local government level. Between 2009/10 and 2014/15, adult social care spending for older people by local authorities has seen a real terms cut of 17%. Recent research suggests that measures designed to counteract the effect of cuts to social care – the council tax precept and the Better Care Fund – will not be sufficient, and that the sector will face an estimated £4.3bn funding shortfall by 2020 (Franklin 2015; LGA 2014).

Cuts to social care budgets have led to an increase in the contribution older people are expected to make to the cost of their care. Between 2005/06 and 2013/14, the percentage of older people receiving social care support from social service departments fell from 15.3% to 9.2%. In the same period, the average annual contribution from individuals towards the cost of care increased by nearly £1000, to £2563 (Mortimer & Green

2015 26: 32). In 2013, it was estimated that the proportion of people self-funding their care and support was 45 % in residential care and 47.6 % in nursing homes (Miller et al. 2013: 3). Research published in 2016 by the Kings Fund and Nuffield Trust (Humphries et al. 2016) points to an exponential growth in self-funded care by older people excluded from public support (see also, chapter 4).

In adult domiciliary care, the number of people receiving local authority funded support across the UK fell by 20 % between 2009 and 2015, and annual local authority expenditure on domiciliary care for older people decreased from £2.1 billion in 2009/10 to £1.8 billion in 2013/14 (UKHCA 2016: 14, 31). The data on the hours of domiciliary care commissioned by local authorities indicates that resources are being focused on fewer people who have a greater level of care need (UKHCA 2016: 28). As with residential care, it appears that a significant number of people are self-funding domiciliary care. The available estimates, which should be used with caution, indicate that about 207,500 people self-funded their domiciliary care in England in 2014/15 – roughly 31% of those receiving such care – spending £652 million in total (UKHCA 2016: 18).

Countering the funding crisis? The social care precept and Better Care fund

England's poorer regions and cities have been particularly hard hit by the cuts to social care funding. The so-called 'Barnet Graph of Doom' (Brindle 2012) pointed to how the twin pressures of financial cut backs and growing demand for adult and children's services would exhaust council budgets, leading to a funding crisis that could not be averted even with efforts to innovate, streamline and outsource local authority services.

'The risk exists that the Barnet Graph of Doom will still come to pass and social care will be the totality of the council budget if we do not have the time and resources to transform what we do. Alternatively social care may become a much smaller version of its former self and then the question will be why are we in this to leave people unsupported and vulnerable. Neither of these scenarios are palatable and leave professionals in this field very uncomfortable.'

(Director of Adult Social Care, Northern Borough Council, written response to CC call for evidence)

In the November 2015 Comprehensive Spending Review, Chancellor George Osborne announced that councils would be allowed to increase council tax by up to 2% in order to fund adult social care (the precept). The Chancellor also announced increases

to the Better Care Fund which would come into effect by 2019/20. However, The Centre for Later Life Funding (ILC-UK;2015) reported in December, that the precept was unlikely to have significant impact on the ability of local authorities to sustain adult social care provision – not least because those councils with the highest concentration of older people and unpaid carers were those that would be bringing in the least amount of money from the 2% council tax rise (Franklin 2015).

'Any funding for pressures in the system are generally channeled through the NHS. This suggests that the political priority is upon A&E targets, but without a general understanding that social care is part of a "whole systems" approach'

(Head of Community Commissioning for Adult Social Care, Southern County Council, written response to CC call for evidence)

Already there is a consensus that the Council Tax precept has failed to stop cuts to adult social care. The Association of Directors of Adult Social Services (ADASS) 2016 budget survey reported that additional cost pressures, in large part due to demographic shifts, were set to leave a funding gap of at least £1.1 billion by 2019–20 (see also, Commons Select Committee, Health 2016). ADASS also noted widespread cuts in spending on services for older people, such as the closure of day centres, the rationing of access to services, reduced eligibility for care provision and the expansion of fees based services. ADASS reported that, although there was a 3% increase in the older population from 2014/15 to 2015/16, there was no increase in the number of older people receiving services. Further, the budget savings that are derived from raising eligibility may also be generating false economies. Savings in the short term may not translate into longer term savings because they merely serve to increase the numbers of older people with acute care needs.

In July 2016, the Commons Health Committee chaired by Dr. Sarah Woolaston MP noted the significant funding shortfalls in the sector and concluded that efficiency savings were not the way forward - 'I would never say there is no more room for efficiencies because there always is, but I think in some cases they have pretty much gone as far as they can go' (Sarah Pickup, cited by the House of Commons Select Committee, Health 2016).

'The key obstacle is managing the increasing population, who are living longer and often with complex needs with a reducing budget. Social Care is vital to ensuring that primary and secondary care are able to function and without the relevant and appropriate levels of funding then we will never be able to redress some of the largest health inequalities.'

(Director of Adult Social Care, London Borough Council, written response to CC call for evidence)

Outsourcing and innovations in public resourcing of care

Many of the local authorities that engaged with the Commission echoed Pickup's sentiment. Commitments to innovations that bring greater efficiencies and, thereby, cost savings are widespread. Telecare, reablement programmes and assistive technologies (see Chapter 5) have been widely adopted in one form or another across local authorities. Innovations in how social care is delivered are also evident in the Greater Manchester area where proposals have been implemented that devolve responsibility for managing an integrated health and social care budget. Integrating health and social is frequently presented as opening up possibilities for increasing efficiencies and generating savings. But many have warned that the integrated budget remains tight, especially given anticipated rising demand for health and social care services. In certain respects it appears that the devoManc/devohealth experiment may be motivated by central government's desire to drive spending cuts by forcing even more responsibility for cuts and spending decisions onto local government (Haughton et al. 2016: 12; Ham 2015)

Innovations in the delivery of social care are occurring against the backdrop of two decades of restructuring of local authority social care provision. This has seen increased commissioning of social care – and similar practices in health care provision – that were developed under the New Labour government's commitment to develop a mixed economy of public service provision (Bovaird, Dickenson & Allen 2012: 19). The term commissioning is applied to this form of social care provision to express an intent to do more than 'buy-in' services. Instead the granting of contracts to deliver services should be based on a range of priorities, a thorough assessment of needs, on-going processes of quality assurance and the monitoring of outcomes (Glasby 2012). The appeal of commissioning, however, also lies in the desire to deliver market efficiencies, or cost-savings, by introducing competitive market pressures into social service delivery.

The marketisation of care is taking place through different channels, including cost saving initiatives. Cost savings in one area often impact the cost of caring elsewhere. In Coventry for example, there has been a significant fall in the number of local council operated care home beds, with plans in place for up to ten council run care homes to be closed. The closure of the local authority run Aylesford care home in 2014 (a short term facility for older people leaving hospital) led to an increased burden on the NHS. This care home is currently being sold off to student housing developers and post hospital intermediate care has now been largely replaced with telecare services. Coventry City Council has continued to close its directly run care homes, with residents

being moved to the private sector. Although the City Council has been involved in partially funding the expansion of private sector accommodation, concerns have been raised about the pay and working conditions of those formerly employed by the Council. Moreover, because the local authority's duty to provide adult social care is not confined to older people, but also extends to adults with disabilities or severe health/mental health/addictions issues, we were told of instances where efficiency savings have led to the establishment of more mixed facilities. In some cases, such facilities – supporting both older people and those with addiction issues – have been established without providing staff with the support and training needed to deal with the complex sets of care needs found in these situations (see also, Chapter 5; Koroma 2016).

Domiciliary care is another area that has seen rapid and extensive marketization. In some instances this has seen services commissioned from small providers catering to particular needs. However, despite the potential for commissioning to deliver bespoke and person-centred services, there is also increased presence from the already large private sector. This often undermines any commitment to bespoke, value-driven, and responsive commissioning in favour of efficiency savings derived via economies of scale and scope. Companies such as Serco or Virgin Care are now big players in the domiciliary care market – holding exclusive contracts with local authorities (National Health Executive 2016). These kind of contracts are sometimes part of 'bundled contracts' that involve a number of different services. In the case of Hertfordshire, for example, Adult and Children's services are provided by Serco alongside highways, environment, and council back-office functions such as HR, IT and payroll.

Outsourcing of public services in this way can have significant, detrimental consequences. It can serve to undermine accountability and the public service ethos, lead to a worsening of pay and working conditions and create moral hazards by shoring up the power and influence of a small number of large multinational corporations (Bowman et al. 2015). Many outsourcing companies are heavily financialized, having leveraged their assets to secure debt backed finance on global markets. This makes them vulnerable to economic shocks and also potentially gives them an unfair advantage relative to local and third sector providers.

Some local authorities have sought to avoid exposure to outsourcing firms, especially in sectors such as social care. However, the pressure to marketise has, as Moriarty et al. (2014) note, seen some third sector organisations behave more like private sector organisations to be competitive. Within this context, many third sector organisations, appear to be having their advocacy roles eclipsed in order to maintain and secure their local authority contracts.

The pressures caused by the involvement of highly-leveraged multinational corporations in delivery are most evident in the home care market, as came to light in the wake of the Southern Cross collapse. Burns et al. (2016) reported on this extensively, documenting the transformation in the 1990s of the home care sector away from small private firms and local authority operations towards a sector where the five largest care chains operating in the UK account for nearly 20% of beds. This expansion has been fuelled by debt-based financial engineering techniques that gave firms access to the finance needed to rapidly increase their market share (and often, at the same time, avoid taxation). Burns et al. argue that the sector is not suited to such risky business behaviours and criticises the lobbying that the sector has engaged in to further capture public funds for increased corporate profitability. Thus whilst there is an urgent need for more public funding for adult social care, important questions need to be asked about where that money would go and who, ultimately, would be the major beneficiaries of any funding increase.

It has been argued in some quarters, including by Burns et al., that heavily financialised care homes should not be bailed out by the State as this creates an unspoken guarantee that fuels such risky behaviours in the first place. The Commission notes that while such a response is unpalatable there is an urgent need to develop sustainable, fair and efficient funding arrangements and regulation that will avoid undue stresses and strains resulting from closures of private homes for older people and their families. The Commissioners also note that these risky business behaviours are, furthermore, part of a more fundamental problem within the care sector: the assumption that families and unpaid carers (and women in particular) will step in at times of crisis to undertake the work of care.

The resourcing of services to support unpaid carers

This report has already noted the false economies that arise when eligibility thresholds for adult social care are raised. It is important to recognise that such practices also have significantly impact on unpaid carers. During our evidence sessions, one director of adult social care commented that '[e]ligibility criteria have been raised here, as in many authorities, so that fewer people are receiving support which can lead to crisis and [unpaid] carer breakdown earlier than otherwise' (Director of Adult Social Care, Northern Borough Council).

Local authorities have a statutory duty to support unpaid carers. The 2014 Care Act stipulates that local authorities needed to ensure that they have in place strategies to identify unpaid carers with needs for support which are not currently met. In Coventry, for example, the Council has developed a carers' strategy that seeks to identify unpaid 'hidden' family carers and to support

them appropriately. The Council certainly recognises that its funding to deliver such a scheme is limited and has sought to work with the local branch of the Carers Trust to expand and adapt their existing programmes in ways that can support local carers.

The support to unpaid carers needs to be considered against the backdrop of local authority spending cuts across the board. Carer strategies developed by local authorities often talk about the role of libraries, community centres and other council run services in assisting with the identification and support of carers. Yet cutbacks have curbed, and are continuing to threaten, these services.

Similar issues are raised by Glasby et al. (2013) who have suggested that local authority efforts to work with local communities to support the needs of carers are potentially jeopardized by local authority cuts. For example, the development of 'social capital' approaches, including the provision of 'citizen hubs' (see also chapter 4) – everyday places that serve the needs of carers and the local community more generally – were undermined by staffing cuts and other efficiency savings. Participants in Glasby et al.'s study expressed similar concerns to many of the local authorities who provided evidence for this report, that social care and support for carers was not seen as an investment that serves an important preventative function.

Baroness Altman's leaked memo:

'I'm afraid this really is a looming crisis which has been left far too long already,' she writes in a memo to No 10 and Oliver Letwin, then a cabinet minister. "This really is an issue that has the potential to cause significant social and economic distress. There has been no real planning for these demographic realities. No money has been set aside in the public or private sector to fund social care if or when the needs arise... We should consider a savings solution.

'We need to encourage people who are already in later life to earmark some of their savings to pay for care, should the need arise. We have been successful in getting people to save in pensions by using tax incentives and I would suggest we need to incentivise care saving too... Most savers who have a few tens of thousands of pounds in their pension funds are probably the kinds of people who are responsible with money, want to look after themselves and their family and do not want to throw themselves on the state.'

The Observer, 9th October, 2016

Given the constraints on funding for social care in most local authorities, many third sector organisations that provide support to unpaid carers have seen public funding for these services disappear. This can lead to a decline in the provision of programmes targeting carers in BAME communities, or programmes targeting carers caring for those with specific needs (e.g. MND or early onset dementia).

Where are we 5 years after Dilnot?

Five years on from the publication of the Dilnot report on the funding of care and support, there appears to be lack of awareness, and recognition, of the economic value of investing in care. Yet the evidence is mounting. Indeed, as a recent leaked memo reported in the press reveals, the government has abandoned even the Dilnot recommendations.

4. Accessing Social Care in an Age of Austerity



There are over a million older people in England who need care but who don't receive it from any public source. As the King's Fund and Nuffield Trust report highlighted recently '[a]ccess to care depends increasingly on what people can afford – and where they live – rather than on what they need. This favours the relatively well off and well informed at the expense of the poorest people, who are reliant on an increasingly threadbare local authority safety net – especially if they live in areas where local authorities have been least able to sustain spending levels' (Humphries et al. 2016: 4). Increasingly it is self-funders and unpaid carers that are having to fill the gap between diminishing publically-financed supply and growing need.

The care landscape outlined in Chapter 2 points to the complexity of the care system. This complexity can lead to confusion about how to access care and what public financial support is available for those requiring long-term care. In this chapter we examine how individuals access the care that they need, the complexities and difficulties that surround gaining access to care, and how this can lead to unjustifiable denials of care.

The key messages in this chapter are as follows:

1. Accessing care involves navigating a complex system of care provision. The personalization agenda has added to this complexity with the cared for and their carers taking on the role of employer and other administrative burdens.
2. The impact of austerity means that for many accessing care becomes increasingly difficult and costly.

Navigating a Complex System

Care delayed is care denied. Yet gaining access to care can be difficult. It is a challenge to establish precisely what kind of social care is available to whom, how it is rationed and means tested and indeed where the individual or family might find advice and information which would help them understand and pursue their entitlement. Often people give up pursuing these entitlements because of the anxiety caused and time needed to access care services. In recognition of these complexities, councils are now

required to facilitate access to independent financial advice to individuals seeking social care to navigate the system of care funding (Brindle 2014; Hopkins & Laurie 2015: 128).

For many, getting information about what services are available to them, a first port of call might be Age UK, which publishes a series of Fact Sheets designed to provide up to date and relevant information. Other organizations such as the Alzheimer's society provide bespoke 'navigator' services for older people suffering memory loss and their families and carers (these were discussed in some detail at our Coventry event). Similar services are provided by organisations such as the Motor Neurone Disease Association and Parkinson's UK, and of course NHS services.

Accessing domiciliary care: the personalisation agenda

Older people eligible for financial support for social care at home can have this provided directly by the local authority or, alternatively, the council will provide a personal budget for them to use towards their care needs. The amount of money depends on assessed needs and can then be spent on any services that meet needs as set down in their care plan. This is called a direct payment. Direct payments in theory allow a person in need of care to be creative and flexible in terms of how and when she accesses care.

'Often where there is an articulate, intelligent, capable family or friend carer then they end up as the Care Coordinator for the person they are caring for. It is not generally anyone from the Practice, Proactive Care Team or any Clinical Team. Least of all the GP or PCT practitioner! It is mostly a question of 'do it yourself'. Professionals so often only focus on their own professional role. For example a GP or Community Nurse would not deem to comment on eligibility for a care package and direct payment – they would just tell the carer or vulnerable person to get in touch with Adult Services. So hand off to the vulnerable person themselves. So often the case!'

(Sue Livett, Aldingbourne Trust, written evidence received by the Care Commission)

The personalisation agenda was intended to guarantee that 'every person who receives support, whether provided by statutory services or funded by themselves, will have choice and control over the shape of that support in all care settings' (Department of Health 2008). The underlying ideological belief is that the introduction of markets in the form of individual budgets will improve the quality of service through flexibility and choice (Spicker 2013: 1267). As of 2013, 412,000 older people were receiving a personal budget, either as a direct payment to a personal account, or managed by their carer, care service provider or local council on their behalf (TLAP 2015: 6).

For some having a direct payments means that older people can choose their own care worker, offering the possibility that they can have a regular care worker rather than different carers each time, which is a major source of discontent for those in receipt of social care. Direct payments can be used to pay someone to help with shopping or attending medical or social appointments. Such flexibility may be desirable, but it also means that the care recipient must take on the duties of an employer and the attendant administrative burden. It is notable that the overwhelming majority of older people in 2013 – approximately 85 % – opted to have a personal budget that was managed on their behalf (Age UK 2013, 7).

Personalisation of budgets also means that the burdens in administering and coordinating care increasingly fall upon friends and relatives. Research by the Social Care Workforce Research Unit at Kings College London points to unpaid carers facing increased levels of stress due to the administration of personal budgets (Woolham et al. 2016). There is an implicit assumption in the care system that families have a spokesperson who not only knows the system but also can engage with and negotiate the system successfully (Katbamna et al. 2004). There is little recognition of the complexity of the regulatory landscape and the difficulties and stress this causes when seeking to exercise choices successfully. Furthermore, within this context, access becomes particularly difficult for members of communities where English might not be the first language and/or from backgrounds where there may be cultural barriers to discussing care needs.

An alternative form of financial support for social care is the Attendance Allowance, which is administered through DWP rather than the local authority and offers eligible individuals over the age of 65 a weekly payment of £82.50 if they need help day and night, and £55.10 for assistance either in the night or the day. However the degree of care need required to qualify for this allowance is much greater than the allowance can pay for, and in any case many older people fail to meet the need criteria and so are not eligible for this payment. In December 2015, the Government published plans to devolve the funding for this allowance to local authorities prompting concern that, given the cuts to local authority funding, many older people and people with disabilities will no longer be eligible for this benefit, and that the funds, which will not be ring-fenced – will be absorbed in the local authority's general social care budget.

Accessing Residential Care

Older people enter residential care when it is deemed that they are no longer capable of remaining at home, even with a care package. Local authorities have an obligation to arrange residential care following an assessment of needs if this is the conclusion. The financial assessment determines how much an individual must contribute to the costs.

Residential care takes place in care homes or in nursing homes where qualified medical staff are present to deal with physical or other disabilities or illnesses. Residential care homes may be directly run by local authorities or privately run by not-for-profit or for-profit private companies. Individuals who qualify for financial assistance may be placed in either, as are those who are self-funding part or all of their care costs.

Nursing homes provide nursing care as well as general day-to-day care and therefore command a higher charge. For people who are seen to have high levels of health-related needs, such as after a disabling accident or surgical procedure, the cost of nursing care is covered by the NHS for the duration of the condition.

Social care rehabilitation services, also termed ('reablement' or intermediate care) must be provided free of charge for at least the first six weeks after a person is discharged from in-patient hospital care or are otherwise entering the care system following a crisis. After this initial period, charges are raised similar to other local authority services. At the Coventry event the Commission heard evidence from Carole Mockford of Warwick Medical School who had conducted a study looking into the issues facing older people with memory loss and their carers during and after this six week period. This research indicated that navigating the health and social care system is extremely difficult, especially when these difficulties are compounded by acute conditions such as dementia.

Carers in this study expressed frustration about the difficulties in navigating the system and expressed fears regarding the financial implications of accessing residential care. This type of care is also subject to significant geographical variation. Some authorities meet local demand to a much greater extent than others whose services have been criticized for falling below statutory requirements. Moreover, private residential home care costs vary across the country. According to Laing & Buisson (2015), average residential home charges per week range from £471 in the North West to £669 in the South East.

Residential care

- There are an estimated 5,153 nursing homes and 12,525 residential homes in the UK.
- According to the latest Laing and Buisson survey, there are 426,000 elderly and disabled people in residential care (including nursing), approximately 405,000 of whom are aged 65 and over.
- The care home resident population for those aged 65 and over has remained almost stable since 2001 with an increase of 0.3%, despite growth of 11.0% in the overall population at this age.
- The gender gap in the older resident care home population has narrowed since 2001. In 2011 there were around 2.8 women for each man aged 65 and over compared to a ratio of 3.3 women for each man in 2001.
- The resident care home population is ageing: in 2011, people aged 85 and over represented 59.2% of the older care home population compared to 56.5% in 2001.

Age UK, 2016, p 14

There are also hidden charges that are not fully explained to the prospective resident and their families – ‘For example, a weekly trip to the hospital, requiring two hours of carer time, could end up costing as much as £5,200 a year. Citizens Advice has provided support to people who have incurred unexpected bills’ (Citizens Advice Bureau, 2016 :4). These issues relating to accessing appropriate, transparent and fair care packages has led the Citizens Advice Bureau to recommend that ‘the Competition and Markets Authority (CMA) should update guidance on unfair terms in care home contracts’ (2016: 5).

The recent report by the Kings Fund and Nuffield Trust further points to an increasing reliance on self-funders to effectively ‘top up’ the cost of running care homes (Humphries et al. 2016:

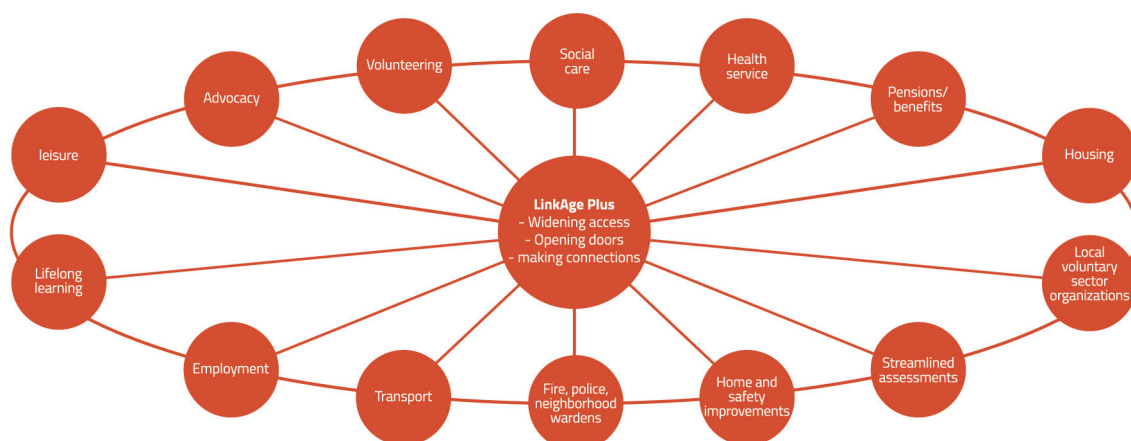
25). In this context, self-funders are seeing dramatic increases in residential care home fees, thus limiting the ability of individuals to access the care that they need. This situation again places increased burdens on friends and family to meet people's care needs and/or to co-ordinate and advocate for better care for their friend or relative.

Link Age Plus – the way to go?

Most older people as well as their relatives are bewildered and often defeated by the complexity of the care system in England as well as the piecemeal system of provision and eligibility for services and funding. There have been some interesting experiments to simplify the task of accessing care. The Blair government built on the idea of Sure Start centres for 0-5 year olds and developed a pilot called Link Age Plus, which was tested from 2006 to 2008 in Devon, Gateshead, Gloucestershire, Lancashire, Leeds, Nottinghamshire, Salford and Tower Hamlets. These were one-stop shops that connected all sections of the community with the services they needed and in so doing also provided centres where older people and their carers could socialise and support each other. Some of these pilots are still running but there has not been a national roll out of this scheme, despite being very positively evaluated (Ritters and Davis 2008). The idea of a central location of information and advice – in other words, a social care hub accessible by everybody regardless of levels of income, need or other support – would do much to improve the obstacles people face in accessing information as well as services, as well as offering an important facility for the whole community.

Figure 3: Linkage Plus

Source: Adapted from Ritters and Davis (2008: 4)



Eligibility for financial support has diminished significantly over the last decade, with no government or political party insisting that provision of social care is a priority for public policy. The financial strains this places on families is compounded by the complexities of accessing care in the first place. This points to, together with the resourcing gaps identified in the previous chapter, the need for a comprehensive overhaul in care provision. To this end, the Commission advocates for the establishment of a National Care Service that is equal to the NHS and free at the point of delivery. The development of local care hubs to provide information and community based services would be part of the National Care Service. Our concluding chapter begins to sketch some of the key elements of a National Care Service that would better deliver for care recipients, carers and ultimately society.



5. Delivering Care



The number of people aged 75 and over is projected to rise by 89.3%, to 9.9 million, by mid-2039. Those aged over 85 – that is, the group most likely to require care – is set to more than double over the same period (ONS 2014). This significant growth begs questions not only about resourcing care but also about scale: how will the care sector scale up care provision in terms of human resources, quality and stability in order to deliver quality care outcomes for a growing older population?

This question is particularly urgent as the sector faces a number of challenges in relation to pay, conditions and workforce development. This chapter presents the results of a survey by the Commission with 169 care workers (the CC Survey), as well as a review of the secondary literature. The key issues identified include that:

1. The growth of private care providers in both the residential and domiciliary sectors has created specific workforce challenges in relation to wages and conditions of work.
2. Workers in the sector take pride in the work that they do, but are dismayed by the lack of recognition for this type of work, not simply in terms of fairer wages, but also in terms of the attitude of successive governments.
3. Lack of training for dealing with clients/residents with complex care needs is a significant workforce development issue
4. Workers involved in delivering care may find their health and wellbeing adversely impacted (or 'depleted') as they struggle to combine the demands of a difficult low paid job with other care and family responsibilities.

Who Cares? The Social Profile of Care Workers and Unpaid Carers

Approximately 1.45 million people work in the adult social care sector in England, more than half work in care homes, three quarters are employed as direct care workers and four fifths are women (Franklin & Brancati 2015: 2). The significant gender imbalance in the care sector workforce reflects a perception of care jobs as low status, low paid and 'women's work' (Oxfam 2009: 4). That said, the presence of men in the sector increased from 12.8% in 2000 to 19.1% in 2010 (Hussein 2011). Men are more

likely to be recruited from outside the sector, work part time, contracted for a larger number of hours per week, and are over-represented in managerial jobs.

Profile of the care workforce

- 52% of the care workforce are full-time
- 36% hold a part-time role
- 23% of jobs in adult social care are estimated to be operating on a zero hour contract, though this figure does not include the large number of workers that may be designated 'self-employed' but are working through generalist agencies that are not seen as 'care' agencies (Skills for Care, 2015).
- Care work is often long term work, with 31% of respondents in the Care Commission survey reporting that they had been caring for over 10 years, 29% for between 4-10% and 36% between 1-3 years.

The proportion of care workers that identifies as BAME stands at 8.7% and proportionally more BAME care workers are men (11.6% v 8%). BAME British workers are more likely than white British workers to be employed on flexible and temporary contracts, working in the private sector and under-represented in managerial posts (Hussein 2011).

Migrant workers account for nearly one-fifth of all care workers looking after older people. There has been a significant rise in the number of new migrants – defined as those who have arrived since 1998 – employed in care work, with migrants constituting 28 per cent of care workers hired in 2007 (Oxfam 2009: 4). Migrant men are concentrated in traditionally female job roles and more likely to work in care homes (Hussein 2011).

Unpaid carers

Older people are both care providers and receivers (sometimes at the same time) and the proportion of older people who are providing unpaid care is rising sharply. Carers UK (2015b: 5) found that 1.2 million people in England aged 65 and over are providing unpaid care, and that the number of carers aged 85 and over grew by 128% in just ten years. Over half (55%) of carers aged 85 and over provide 50 or more hours of care a week.

As we have seen in chapter 2, thousands of people care for older people but without recompense or wages. These unpaid carers

are the backbone of the care system, yet get little recognition. The State of Caring Report 2015 by Carers UK notes that over the next five year Parliament, 10.6 million people will take on a new caring role for a disabled, older or seriously ill relative or friend (2015b: 5). They also note that 76% of carers believe that caring impacts negatively on their health and well-being, 61% are worried about the negative impact it has on their relationships with friends and family (ibid.: 8-9) and nearly half are struggling to make ends meet (p.10). Respite and support for carers then is an important issue.

The impact of privatisation on the care workforce

The Women's Budget Group have noted that instead of increasing funding to meet rising demand, successive governments have tried to reduce social care costs by outsourcing it to the private sector (WBG 2015). This privatisation of care has had important implications for care workers. One of the key themes emerging from the Commission's Coventry event was that care workers are concerned about the increased uncertainty surrounding their jobs due to fears of further cuts to local government funding. Marketisation generates anxiety for both care receivers and care workers.

The extent of privatisation was evident in the CC survey. A majority of the CC Survey respondents worked for either a private care provider (48%) or in domiciliary care (37%). Just 8% said that they currently or most recently worked for a public provider of residential care, 4% for a public provider of domiciliary care, 2% as personal care assistant. 58% of respondents found their job through the Job Centre, 22% through direct application and 10% through agencies. This distribution has an effect on the vulnerability of care workers and their ability to mobilise to represent their own interests.

Indeed, union membership among unqualified care workers working in the domiciliary realm or as support workers is, at 24%, significantly lower than the level of unionisation of care managers (58%) and qualified social workers (88%) (CommunityCare 2011). The low level of union representation among the care workforce impacts their bargaining position. According to a representative of UNISON who was present at our Coventry evidence gathering event, the level of union representation among the private sector care workforce tends to be significant lower than among those directly employed by local authorities. This in part may explain why care employees in the private sector earn less on average and have more limited entitlements to leave, sick pay and pension provisions than in the public sector (Land and Lewis 1998: 63). One study estimated that between 150,000 and 220,000 care workers were being paid below the minimum wage in 2011

(Ramesh 2013). Heather Wakefield, Head of Local Government at UNISON, argued during our London evidence-gathering event that privatisation has 'put great burdens on staff, in the form of pressure on visiting times, a lack of training to deal with care needs, as well as new forms of surveillance and control of home workers (through swipe cards and 'dialling in')'.

The 2015 July Budget introduced the new Living Wage for those aged 25 and over. While there is an urgent need to increase wages for low-paid care workers, without additional funding to the sector there are questions as to how the cost of this will be met. Ingham et al. (2015) estimate that 'The estimated annual wage cost of paying the living wage to all care home staff in 2014 is £830 million for the UK, increasing to almost £1 billion when National Insurance and pension contributions are factored in'. They argue that [the] new living wage announced in the Summer 2015 budget will affect at least 50% of care home workers. Including National Insurance and pension contributions, it would cost £387 million per year for the UK. Proposed reductions to in-work benefits mean that many low-income households will [therefore], lose out on any potential gains in income'.

Migrant care workers providing care for older people work primarily for private employers but some are self-employed. This category has been found particularly vulnerable to exploitation by agencies (Oxfam 2009). Migrant workers work longer hours and do more night shifts than their native peers. The reasons why migrant workers accept these conditions have been addressed in terms of comparatively better pay than in their country of origin, problems in finding other work, and their legal status – where those dependent on work permits are often restricted from changing jobs (van Hooren 2012: 134). It is also worth noting that the expectations of public support for these migrant care workers is likely to be negligible. Regardless of the outcome of the Brexit discussions, short term migrants whose right to remain in the UK depends on being in employment would not necessarily expect public support in this country either for their own elderly relatives or themselves when they reach retirement age (though this will depend on precise reciprocal arrangements with different countries and migrant employment regulation. This begs a lot of questions. The status of many migrant care workers is often unclear. Those employed through an employment agency frequently sign away any employment rights, including pensions and other forms of social support in the future, with a built-in assumption that when they cease to be able to be gainfully employed they will 'go back to where they came from' whether or not they have formed family or community ties in the UK.

The impact of telecare on recipients and providers of carer

Telecare is increasing as a mode of care delivery. This term includes monitoring the quality of care being provided, for example via electronic clocking in and out, as well as computerised aids and sensors for delivery of care.

According to one estimate, there are now 1.7 million telecare users in the UK. It is intended to enable independent and safe living.

Telecare products range from panic buttons and alarms connected to care and emergency services to complex and comprehensive sensors in rooms, baths, gas appliances, and pill dispensers. These products can provide 24-hour monitoring and has the advantage that it allows for multi-lingual services.

A randomised trial based assessment showed that telecare to have some positive results, including a 45% reduction in mortality rates, 20% reduction in emergency admissions, 15% reduction in

A&E visits, 14% reduction in elective admissions, 14% reduction in bed days and 8% reduction in tariff costs (Steventon et al. 2012).

However, there are concerns that the use of apps and technological devices presumes familiarity with technology that is not present among older or less educated carers and care workers. There is also a concern that some telecare monitoring systems, including the increased use of devices to track and monitor care worker locations, may infringe workers' rights and be intrusive and disciplining, rather than enabling.

Further, while the positive results seen in initial assessments of telecare suggest the further expansion of this service is desirable, there is a question about the impact of telecare on the more general well-being of care recipients. Loneliness, boredom and marginalisation cannot be addressed by these technological solutions.

Being a care worker: key findings from the CC survey and literature

Privatisation, marketization and domestication of care is building up to a crisis of care, including the workforce. Below we outline the most important issues that emerged from our survey of care workers and the secondary literature. These highlight the difficulties that they face every day in caring for others, which often does not leave enough time to care for themselves and their families.

Recognition

'...the questionnaire !!! I did not enjoy doing it !!!... I didn't like doing it as it made me think how stressful & unfair my role is as a PA/ carer -totally unappreciated at times! (CC Survey 169)

These words of a private care assistant alert us to the stresses and strains are faced by care workers when the value of their work is not recognised or appreciated. Given the low pay and poor working conditions in the sector, it is perhaps not surprising that care workers responding to our survey said they were motivated by serving those in need and the work being emotionally

rewarding. Indeed, when asked about rates of pay, the majority of respondents (54%) said this was the least important motivation for engaging in care work and, tellingly, no respondents listed it as the most important motivation. By contrast, when asked whether the fact that the work was emotionally rewarding or whether they enjoyed caring for others, 62% of respondents said this was their most important motivation.

And yet, lack of recognition and appreciation was a serious issue for many. One respondent said, 'As carers we are unsung [heroes] in our jobs, we are classed as the underdogs' (CC Survey 55). Another commented:

Working as a carer is undervalued by society but the clients worry about the cost, they are charged up to £17.00per hour, carers are paid less than half that amount, its all about profit these days. Employers should value good carers who are often isolated. Palliative care is very stressful, rewarding but undervalued. Carers are carrying out work that once was a role for the district nurse for a lesser rate of course (CC Survey 4).

The comments of this respondent clearly link recognition and pay; pay as recognition for the work done, and as a fair wage. The lack of recognition also affects the turnover rates in the sector; the Cavendish Review found a 19% turnover rate per year in care homes and up to 30% a year in domiciliary care and linked this to a sense of 'being only a carer' (Cavendish 2013: 6).

Unionised and non-unionised work

In our survey, 74% of respondents reported that they are not a member of a trade union, while 26% are unionised. As we saw earlier, lack of unionisation adversely affects care workers' pay and working conditions. Migrant care workers are especially vulnerable due to a lack of effective employment rights enforcement in the sector. Under the current regime, workers must seek redress for their grievances through an employment tribunal or other enforcement agency as agencies in the care sector are ineffectively regulated by EAS (Employment Agency Standards Inspectorate). There have been demands for the care sector to be brought under the remit of the Gangmasters Licensing Authority (GLA). Licensing of agencies by the GLA would ensure that only those agencies which respect employment rights, pay the minimum wage, and do not subject workers to debt bondage, harsh treatment or intimidation can employ care workers.

Complex Needs

Medical needs, mental health problems and behavioural issues make for complex needs that care workers have to address. The Commission was told that integration of different types of care is increasing as local authorities increasingly outsource to generalised providers. The combination of these factors is making care delivery more complex. One care worker reported that '....most people you go see expect you to have a good medical knowledge, when all we have is basic first aid' (CC Survey, 113). Delivery of complex care requires better and more intensive training for staff. And staff, in turn, should have these skills recognised by regulatory bodies and in their level of pay.

Training

Ipsos-Mori identified developing and training 'as a priority for delivering improvements in quality, personalisation, integration and prevention' (Ipsos-Mori 2012:8). The Cavendish Review, however, found that there are huge variations in terms of the quality and quantity of training provided (Cavendish 2013: 7). Our survey shows that GCSC or O levels are something of a baseline qualifications for care workers (65% hold these); 14% reported that they hold a professional qualification, and 6% had a degree. But most respondents also reported that their job did not require them to have a specific qualification (74%). This finding is in line with the King's Fund and Nuffield study (2016:7) which reported that 37% of care workers surveyed had no recognisable qualifications. The Cavendish Review (2013) identified a disconnect within and between NHS and the social care sector, especially in terms of the training standards for healthcare assistants and social care support workers. The lack of coherent training opportunities contribute to workers being undervalued, lack of career progression, and confusion among care recipients. The review proposed new common training standards across health and social care – a 'Certificate of Fundamental Care' which links healthcare assistants to nurse training for the first time.

Travel

Despite policies regarding travel expenses, care workers often subsidise the private sector by paying for their own travel. One of the CC Survey respondents had to take her employer to court for enforcement; she wrote: 'Carers SAVE the government money and this should be recognised. I had to take my ex-employer to court to get the pay for travel time that was due to me.... I should not have had to take this action!' (CC Survey 46). 60% of homecare workers (and 93% of commissioned carers) are not paid for travel time, that workers often have to provide their own car and mobile phone, launder their own uniforms, and even have the company badge to sewn on themselves. In a recent class action against a service provider – Sevacare – one carer complained that she 'visited all of her clients by bus. But there were some days...when she spent more time trying to get to her clients than caring for them - she could spend seven hours travelling each day and not be paid for it' (Conway 2016).

In some instances staff are paid less than the minimum wage, because not all time they spend at work is counted (e.g. time spent waiting, travelling between clients, or spending longer with a client than allocated). One of the CC Survey respondents commented: 'our company says we are paid travel time included in the hourly wage. If this the case then we are paid under minimum and living [wage] (CC Survey 48).' Another commented that it was only because they were not being paid for travel time that they found it hard to balance care work and their private life. 49% of the CC Survey respondents travel for more than one hour to work per day; 16% travel 1-2 hours and 12% more than 3 hours per day.

Time

Call-cramming, long travel and insufficient time to do their job is stressful and undermines the work of carers. UNISON research shows that 74% of councils in England are still commissioning 15-minute homecare visits and that 5-min visits are in existence. A respondent to the Commission's Survey complained: '...service users remember when you leave 5 minutes early but never remember the time you stayed back an extra 20 minutes UNPAID because they were not well..... carers do a lot of unpaid work like collecting meds, taking samples to doctors, etc..... family get mad with you because of the hours you work' (CC Survey, 113). Despite sustained public debate and lobbying by care groups as well as unions, this issue is not been addressed by many local authorities. As a recent UNISON report – *Suffering Alone at Home* – stated, 'Three quarters (74 per cent) of local authorities in England are still limiting homecare visits for their elderly, ill and disabled residents to just 15 minutes' (2016:3). Some local authorities such as Nottingham, however, have heeded UNISON's call for an employer ethical care charter in the sector.

Depletion

Rai et al. (2014) have suggested that depletion of individuals, households and communities engaged in social reproductive activities such as caring occurs when the inputs into their lives (recognition, health, rest, leisure and food) fall short of the outputs (care work, paid work, responsibility for managing care) that they have to produce. The lack of timely access to health services, childcare and time produce anxiety and stress, which are important elements that can lead to depletion. At our event in Coventry, Shereen Hussein of Kings College London presented evidence based on her research on the social care workforce to the Commission and highlighted that care workers were in the 'amber/red' zone of psychological work stress (Hussein 2016). Precariousness of jobs – not just zero hour contracts but also an irregular work pattern (45% of CC Survey respondents have irregular work patterns), and work in multiple locations that can lead to greater travel (30% of CC Survey respondents work in more than 5 locations and 10% in 2-5 locations) can adversely affect the well-being of care workers. Long travel time can lead to the extension of the working day, greater tiredness and vulnerability to illness. In the CC survey, 60% of respondents work more than 8 hours a day. Hussein outlined for the Commission the leading causes of care workers resigning from their jobs: insecurity, lack of job progression and work based stress.

Depletion of care workers is also affected by fiscal austerity – childcare provision has become more difficult with the erosion of the child tax credit scheme (UN 2016), pressures on health budgets have meant increasing number of people are unable to access health care (Royal College of Physicians 2012), and the growing imbalance between the aging population demographic, the decreasing central government contribution to local authorities and the decreasing care sector workforce all of which adversely affects the work and well-being of the care worker.

There is some evidence that the squeeze on resources means that welfare benefits are being linked more and more closely to finding employment, which of course is a gendered market; this means that women are increasingly being pushed into care work as means of getting them off the benefits register.

Delivering care to older people in England is an urgent task that is being carried out under extremely stressful conditions that ultimately undermine the quality of care and threaten the sustainability of the care sector. Those delivering care in the formal sector are often faced with low pay and poor working conditions, while the growing number of unpaid carers receive no compensation at all. For paid and unpaid carers, depletion is a serious concern. But it should be a concern for society as a whole. Placing too great a burden on either paid or unpaid carers may well risk breaking the care system.

6. Out of Sight, Out of Mind



In this chapter we review the key issues identified by the Commission that either do not get much public attention, or aspects of which are obscured in public discourse and policy making. In particular, we wish to highlight the complexity of issues that those who need care, carers and care workers face so that these can be addressed not piecemeal but in an integrated fashion in policy and research.

Efficiency v resources/ resourcing

Austerity is not working for older people in need of social care in England. Together with others before us, in the report we have argued that the government needs to increase local authority budgets for social care in a systematic way in order to address the funding crisis and ameliorate geographical inequalities.

In this respect, precepts are not sufficient. Core funding for social care needs to be increased and stabilized. While we are convinced that Dilnot recommendations, however flawed, need to be implemented in full, we also endorse the view that the Dilnot commission could have 'gone the whole nine yards [to argue] for a free social care system funded from general taxation that can connect seamlessly with a universalist NHS. This is what most service users and members of the public appear to favour and is acknowledged to be the simplest and clearest funding model' (Beresford, 2011).

Ways of delivering care for older people

While appropriate funding of social care is an important issue, we question whether there is enough discussion in public debates of improved ways of providing care for older people. This is not to suggest a 'leaner, meaner' social service; rather we note the need for improved and greater joined up thinking on delivery of care. One issue that we have noted particularly, for example, is that of the complexity of accessing care – the labyrinthine nature of care services and provision place added burdens on those who are caring. Can we simplify access? What administrative measures work and which ones do not? How can revisions in policy provisions be flexible, accountable and transparent? What role can participation of those who are cared for be 'regularised' to feed into discussions about improving services? As we have seen, the complexity of institutions that provide and regulate services

means that service users are unclear about which way to turn when in need. The establishment of a National Care Service may also go some way to addressing these issues.

Recognition v Provision for BAME communities

As we researched and spoke with carers, care workers and those cared for, the issue of provision for BAME communities became prominent. It became evident that although as a society and a polity, identity groups have far greater recognition the resources to provide or care for them is far from adequate. This gap between recognition and provision can be seen in the lack of specialist services. It is also because the mobilisation of interests of identity groups is poor – levels of participation of older people in BAME communities for example are affected by lack of English language abilities, lack of public facilities for translation, and also because of variable levels of education among these communities. Another assumption that is often made for Asian communities in particular is that the joint family system continues and provides for older people so public services don't have to deal with this group of people. All these are problematic assumptions that lead to poor funding for services and regulation of special services for minority identity groups. As we have discussed above dementia related issues are particularly difficult to resolve within the community and need to be supported through public funding.

Complexity of health issues and impact on care

According to the Carers Trust, 1.5 million people care for someone with mental ill health in the UK (2013). Mental health is a growing area of concern for older people, both as recipients of care and as carers. The complexity of mental health needs often goes unrecognised because of the wide spectrum of conditions associated with it; this might include dementia, Alzheimer's, anxiety and phobias, depression, and psychosis. Carers and care workers face far greater challenges in identifying these complex needs than if the care recipient is solely physically challenged. These challenges of identification, accessing the appropriate health services and care facilities can put enormous strain on carers and care workers.

Mental health issues also are often spoken about without seeing training as an integral part of it. In chapter 5, we have already commented on the low levels of training that care workers are given and the need for better and all-round training. Complex mental health needs require robust and high levels of training of staff and also of unpaid carers, who are often the ones that face most of the everyday pressures of care and responsibility.

Unpaid Care Work

As feminist political economists writing on care, we are acutely aware of the low priority afforded to the labour of unpaid carers on the policy agenda, even though some progress is being made in this regard because of the work of campaigning organisations such as the Women's Budget Group (WBG) and academic work (Elson, 2002; Hoskyns & Rai 2007; Pearson & Elson 2015). While some attempts have been made to support carers through provision of respite care and carers' allowance, these are not enough and operate under considerable constraints and have also themselves been undermined by austerity policies. Unpaid care work needs to be given much greater recognition and support if we are to mitigate the depletion of physical and mental well-being of carers (Rai et al. 2014) and ensure that they are able to provide care on a sustainable basis.

'Not long after I became mum's carer I had a family of my own. I found this time in my life particularly difficult; unable to lean on mum for support in raising my children, feeling robbed of the relationship I imagined there would be between my mum and my children'

Former carer speaking at the Coventry Care Commission Event 'The Work of Care', March 2016.

In this report, we have tried to outline the physical, emotional and mental costs of caring, which we have termed 'depletion' (see Chapter 5). A study from John Hopkins University suggests that 'Caregivers who provided "substantial help" with health care ...were roughly twice as likely to experience physical, financial and emotional difficulties as those who did not provide that help' (Wolff et al. 2016). While depletion can be offset through different strategies, we have to be aware that this can also increase the depletion of others if public funding for care continues to decrease. Buying in private care, for example if not compensated adequately through the Living Wage, might have the effect of mitigating the depletion of the employer at the cost of increased depletion of the care worker. Depletion can then be a good measure for seeing what needs to be done to improve the lives of both those who care and those who are cared for. The struggle for a better 'reproductive bargain' (i.e. how households make decisions about how paid and unpaid work is combined and how these decisions frequently place women at a disadvantage), or strategies of replenishment through state or non-state social provision, is then important for sustainable provision of care of older citizens.

Migrant workers – who cares for the carers?

As we have pointed out in this report, migrant workers provide a considerable amount of care within the English social care system. This is especially true for London and South East England. We have raised the issue of conditions of work for migrant workers. While it is recognised that we need to lessen the exploitation of migrant workers and that they need to be paid reasonable wages and have good conditions of work, we also need to bring to notice the fact that many of the migrant care workers have care responsibilities in their home countries, which add to their labour and working day. These responsibilities compound anxieties and can erode their living conditions in England as they send money (remittances) to their families. The debates about migration and Englishness can make them feel vulnerable and unwanted, which can also erode their confidence and well-being. Addressing the question of 'who cares for the carers?' within this context is important. The migrant workforce, of course, faces much uncertainty with Britain's impending exit from the EU and public and policy discourses that favour stricter migration regimes.

7. Conclusions & Recommendations



A system in crisis

The Commissioners found that the social care system is unsustainable and in crisis. Sustained under-funding, exacerbated by austerity policies over the last decade and a dysfunctional care system, has caused this crisis. A lack of political will to solve it has perpetuated it. But the problem is not going away. Instead it is growing as our population ages and more people face older age with chronic ill health and multiple conditions. The number of people who are living with unmet care needs has increased and yet the spend on the care of older people has fallen in real terms.

Gendered norms of caring mean that there is an assumption that women will step in to provide care and compensate for the services that the state is failing to provide. But looking ahead we face a shortage of both paid and unpaid carers. Women are more active than ever in the formal labour market. Their paid work will become increasingly difficult to reconcile with unpaid caring responsibilities. Stricter migration regimes, which look likely to be implemented over the coming years, threaten the supply of workers in the formal care sector.

The system, as it currently stands, is failing care recipients. They often do not get what they need and feel they must be grateful for what they do get. At best the system is functioning to give people what is needed to exist and is far from providing a personalised care service focused on raising their capabilities and helping them feel cared for. It is also a one size fits all system and does not respond to the needs of particular groups such as BAME and LGBT QI people.

The deficiencies of the care system directly increase costs elsewhere. These deficiencies result in preventable hospital admissions, causing queues in A&E and cancelled operations, and force the NHS to hold patients who no longer need medical care in wards because they do not have the support to go home.

Finally, those who provide care are ill-served by the system. Underfunding and the involvement of the private sector means tight budgets must be stretched if a profit is to be produced. Often this occurs at the expense of care workers and those they care for, and leaves provision insecure if providers cannot sustain their business model. Low pay, poor working conditions and negligible career prospects are endemic in the sector. This cannot be a basis for good quality and sustainable care.

As outlined in chapter 3 and 4, there is pressure on paid care workers and unpaid carers which adversely affects their ability to look after themselves and may prevent them supporting other dependents, including children. These pressures result in over two million unpaid carers dropping out of the labour market (Carers UK 2013). Women also find it difficult to return to work, which contributes to a persistent gender gap in earning and pensions.

Why isn't social care a political priority?

Despite repeated attempts in the past few years, resolving our care crisis is not a political priority. The Commission suggests this is the result of a number of interwoven factors:

1. The size of the problem is seen by many as 'too big' to tackle. There is a view that it is financially unaffordable to provide good quality care for all who need it, instead of a recognition that a failing care system is costly in social and economic terms.
2. The assumption that 'someone will step in' to keep the system going and, more specifically, that women will step in to do unpaid caring or work, particularly if they are migrants, or unemployed, for low pay and under poor conditions.
3. The lack of concern about, and value placed on, the lives of older people and carers. Despite talk of the 'grey vote' older peoples' concerns are overlooked through a lack of cross-party political consensus on a way forward.
4. The assumption that 'anyone can care' leads to caring being regarded as low status and unskilled work, not requiring training and continuous professional development.

The way forward?

The current government appears to be pursuing only one strategy for addressing the crisis of social care – individual saving for old age. However, this is highly inefficient and unreliable, as well as raising important questions about fairness and equality. Individual needs for care in old age are extremely variable and unpredictable. They are not determined by, and often will not reflect, how much we have been willing or able to save. Women, who as primary carers tend to have lower earnings and more time out of the labour force, will be doubly disadvantaged: they will have less ability to save for their own care and be left to pick up the pieces when relatives or friends have unmet care needs.

But there is an alternative. The government can provide collective insurance for care needs by investing in care. This could be financed by a care levy – a tax hypothecated for spending on care – that would reduce the uncertainty of individual saving.

Research by the Women's Budget Group, presented at the Commission's London event, demonstrates that public investment in care makes economic and social sense (Taylor 2016). Economic modelling has shown that investment in the care sector creates more employment and economic output than a comparable investment in construction (De Henau et al. 2016). Both physical and social infrastructure are vital. If money can be found to fund physical infrastructure projects, some of it would be better spent on investing in our care infrastructure to meet urgent needs while at the same time generating employment and economic growth.

Fundamentally, as a society we need to provide for older people – not only for economic reasons but to secure a fair and caring society where everyone gets the support they need, irrespective of their colour, class or creed.

Recommendations

Care must be central to policy decision-making in order to ensure that society is able to provide for its most vulnerable. To this end, we recommend:

1. ESTABLISH A NATIONAL CARE SERVICE

The Government should:

- Give social care equal status with the NHS and establish a National Care Service, which would aim to provide care free at the point of delivery.
- Minimum standards must be established and strictly enforced, while preserving diversity of provision. These standards should aim to provide care that we would all wish to receive for ourselves and our loved ones. In particular, these

standards should include the following:

- The voices of care recipients and carers incorporated into policymaking and shaping service delivery through systematic channels of communication and representation
 - A personalised and person-centred care service for all those in receipt of care.
 - A service that meets the diverse needs of our population including BAME, disabled and LGBTQI people.
 - Increased resources for those living with alcohol or drug misuse or mental health problems.
 - Commitments to ageing better with a focus on prevention and on enhancing care recipients' capabilities which might support independent living.
 - A preventative approach that communicates a healthy, active living agenda to younger generations in order to reduce demands on social care services in the future.
 - A trained, professional workforce able to respond to the complex needs of older people, including those living with dementia, chronic or multiple conditions.
 - Intelligent use of technology where it enhances the quality of care without diminishing caring responsibilities and relationships.
- Assess and implement findings of pilot projects which are working towards integrating health and social care for older people who have undergone hospital treatment.
 - Strengthen regulations to ensure private sector providers of care maintain good quality and sustainable provision for recipients of care and their families.
 - Redesign the commissioning system so that both public sector and small local private care providers are able to compete on a level playing field with large corporate providers.

2. INVEST IN THE SOCIAL CARE INFRASTRUCTURE

- The Government should take the opportunity afforded by the relaxation of the fiscal rules and the move away from pursuing a budget surplus in 2020, to invest in the social care infrastructure.
- Reductions in central grants to local authorities should be reversed. Social care expenditure should be regarded as a form of infrastructure spending.
- Introduce a social care levy which would be redistributive and used to fund good quality social care for all.

Local authorities should:

- Recognise the economic and social benefits of care spending in their local communities and budgets.

- Calculate the numbers of people living in their area with unmet care needs and set targets to rapidly reduce this number over time.
- Review the current plans for care services for the short, medium and long term to ensure they are effective
- The Care Quality Commission should monitor local authority performance against these improved plans.

New Combined authorities and Metro Mayors should:

- Use the opportunity presented by devolution to create a sustainable social care infrastructure in their region

3. PROFESSIONALISE AND SUPPORT THE CARE WORKFORCE

The Government should establish 'Care First' – a new initiative which would:

- Professionalise the social care workforce, raising standards and pay. Establish a national policy on recruitment and training of domiciliary and residential care workers, with a new qualification which will bridge the gap between care workers and nurses to deal with increasing complex care needs.
- Create career pathways for the social care workforce, including into and out of the health service, to prevent women being trapped in low paid, insecure work.
- Address workforce shortages and improve standards of care. This would include the implementation of UNISON's Ethical Care charter and other steps to ensure appropriate remuneration, contract and non-wage benefits for care workers at all levels.
- Give social care workers keyworker status, providing them eligibility for housing support.
- Set targets to get more women into management levels and more men into social care, challenging gender norms and stereotypes and helping to close the gender pay gap.
- Immediately guarantee that all EU migrant workers in the social care workforce will be allowed to remain in the UK.

4. RECOGNITION AND SUPPORT FOR ALL UNPAID CARERS

The Government should:

- Establish and promote a national source of information and guidance for individuals and family members about entitlements, availability of different services, and assessments.
- Ensure that any consideration of intergenerational fairness recognises the value of unpaid care work by relatives and friends, the depletion they experience in doing this work and provides appropriate services to support them.
- Introduce a new entitlement to family leave so that carers are able to take time off work without losing their jobs. At least part of this entitlement should be paid leave.
- Drive a culture of flexibility for employees in the workplace. Progress from the right to request flexible working to a presumption of flexibility so that all jobs are offered on a flexible working basis unless there is a business case for them not to be.
- Invest in supporting carers to return to work. Incentivise employers to employ people with caring responsibilities and tighten legislation to prevent them being discriminated against at work.

Appendix: Organisations and individuals consulted

Many different organisations and individuals contributed to our work– speaking at our events in Coventry and London, writing written submissions, giving us their time and agreeing to be interviewed in person, and reviewing and commenting on our work. These include:

Abigail Watson, Family & Childcare Trust
 Aliyyah-Begum Nasser, Maslaha
 Andrew Curtis, Oxfam
 Barnsley Metropolitan Borough Council
 Ben Franklin, International Longevity Centre – UK
 Bracknell Forest Council
 Bridget West, Government Equalities Office
 Carers Support, West Sussex
 Carole Mockford, University of Warwick Medical School & the SHARED study team lay researchers (Sue Boex, Yvonne Diment, Richard Grant and Uma Sharma)
 Caroline Abrahams, Age UK
 Caroline Bernard, NHS Providers
 Catherine Dale, Councillor, Southwark Council
 Cheshire West and Chester Borough Council
 Chris Payne, ONS
 Clare Glasman, WinVisible
 Damian Gannon, Chair of Coventry Health Overview & Scrutiny Committee, Coventry City Council
 David Truswell, Culture Dementia UK
 Dawn Palmer-Ward, UNISON Coventry City Branch
 Derby City Council
 Edie Chan, Chinese National Healthy Living Centre
 Elizabeth Woodcraft, carer
 Ellen Harris, Fawcett North London
 Emily Holzhausen, Carers UK
 Emma Dowling, University of Middlesex
 Emma Holland-Lindsay, National Federation of Women's Institutes
 Emma McKay, Young Women's Trust
 Fae Garland, University of Exeter
 Fiona Mactaggart MP
 Fran Scott & Steve Cooper, CareWatch, Leamington Spa
 Frances Scott, 50:50 Campaign
 Gabriel Siles-Brugge, University of Warwick and Health & Trade Network
 George Sands, UNISON Coventry City Branch
 Halton Borough Council
 Hampshire County Council
 Heather Wakefield, UNISON
 Helen Jackson, Women's Budget Group
 Ila Chandavarkar, Women's Resource Group
 Iman Achara, British Black Anti-Poverty Network
 Janet Morrison, Independent Age
 Jennifer Lynch, University of Warwick
 Jeremy Roche, Open University
 Jerome De Henau, Open University
 Jill Rutter, Family & Childcare Trust

Judy Downey, The Relatives & Residents Association
 Karen Constantine, Royal College of Midwives
 Kath Parson, Older People's Advocacy Alliance
 Katharine Chapman, Living Wage Foundation
 Kim Sparrow, Global Women's Strike
 Lancaster County Council
 Laura Bennett, Carers Trust
 Laura Gardiner, The Resolution Foundation
 Leeds City Council
 Linda Kaucher, Independent trade researcher
 Lisa Plotkin, National Federation of Women's Institutes
 Liverpool City Council
 Liz Law, Equality Commission of Northern Ireland
 Manchester City Council
 Mary Larkin, Open University
 Matthew Egan, UNISON
 Matthew Wills, University of York
 National Care Association
 Nnanna Uwakwe, The Alzheimer's Society, Waltham Forest
 Paul Bywaters, University of Coventry
 Richard Humphries, The Kings Fund
 Rochdale Metropolitan County Council
 Rose Hunt, UNISON Coventry City Branch
 Sarah Wellard, Grandparents Plus
 Saskia Goldman, Care England
 Scarlet Harris, TUC
 Sheffield City Council
 Shereen Hussein, Kings College London
 Stephen Burke, United for all Ages
 Sue Lawler, Carer's Lead, Coventry City Council
 Susan Himmelweit, The Open University
 The Alzheimer's Society, Coventry
 Trevor Brockelbank, Homeinstead
 Vanessa Olorenshaw, Independent Researcher
 Wiltshire County Council
 York City Council

The work presented in this report draws upon the evidence provided by these organisations and individuals. The final report reflects the views of the authors and not those of specific organisations and individuals listed above.

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